

I found this paper very interesting. Hope you do also.

Regards,

  
Jerry Walsh

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THE GROWTH OF AWARENESS

conversations with mentally retarded persons

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"In order to rehabilitate the victims of institutionalization who are vegetating in our hospitals, first and foremost - before establishing around them some new, welcoming and humane environment they have need of - we must apply our strength to arousing within them a sense of opposition to the power which until now has ruled over them and made them part of the institutional furniture. If this sense can be revived, the emotional vacuum in which the patient has been dwelling for years will begin to be filled with personal forces and reactions, with conflicts and with the aggressiveness which is the only material out of which his continuing rehabilitation can be fashioned ..."

Franco Basaglia

You have to choose sides

As a recently appointed social worker at a large institution, I was immediately confronted with situations where ordinary values were not expected to apply. It was obvious that the people living in the institution were suffering harm as a result of conditions there, and I was expected to concede that nothing could be done about it. I realized that I had to choose between regarding the mentally retarded as "objects" not having the same needs and rights as the rest of us and regarding them as a group of people who had been deprived of their rights as human beings. It soon became quite clear to me that I would be forced to choose sides. I had to decide whether I wanted to be a party to the manipulation and control of the mentally retarded or whether I wanted to establish a relationship with them as if they were people capable of altering the conditions in which they were living.

Emancipatory pedagogics

The group activities conducted with mentally retarded people are usually predominantly pedagogical in character. The aim is to provide the mentally retarded with knowledge about themselves and their surroundings. The pedagogics which I find useful is the emancipatory pedagogics in which you take the living

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situation of the members of the group as your starting point by developing the antitheses which are latent within it. As the members of the group become aware of the conditions in which they are living, they discover their true interests and needs and are then in a better position to influence and transform their situation.

Traditional group interview methods mainly focus on an investigation of the relationship between individuals or between individual and group. As a rule they make little use of models of the way in which individuals or a group will be able to influence their surroundings or "society".

The situations in which I felt I was best able to realize my intentions were in discussion groups together with mentally retarded persons, where together we tried to act on our need for emancipation. The mentally retarded members of the group worked to become aware of the limits which the institutional structure imposed on their actions. I worked to emancipate myself from the expectations confronting me as an officer of an administrative authority which "took care of" mentally retarded persons. We all worked on ideas within ourselves which impeded our development.

These group discussions cannot be regarded as group psychotherapy, because instead of being developed on a psychodynamic foundation they focussed on the current social situation of the members of the group. But this is not to say that the social dimensions completely exclude the psychological ones.

#### Basic assumptions

Marxist theory maintains that man is an active and acting being who creates himself through his actions. Man cannot be "silent". A person faced with a situation in which he is silenced and denied opportunities of action breaks down as a result. This is what happens in total institutions.

The individual is responsible for his actions, and there is always an intention behind that which he expresses. As an individual one has to choose between alternative courses of action, one has to choose a standpoint in every situation. Passiveness, irresponsibility and stereotype action are among the alternative courses of action which a person can opt for.

But at the same time a person's actions are determined by his material conditions, the environment in which he lives and the influences to which he is subjected. People create their own conditions and are shaped by their conditions in a process of interaction. Man is capable of transcending himself and transforming his living conditions.

Awareness is a key word in emancipatory pedagogics. Man often has a limited awareness of "insuperable" barriers; he regards himself and is defined by others as a victim of circumstances. By taking actions which are aimed at transcending and overcoming rather than passively accepting what is given, what is known, man can conquer the "circumstances" which are conquering him. By taking new and untried courses of action, man can heighten his awareness of untried possibilities. Man is changed by changing.

The true relationship between two people is a mutual relationship between two subjects where neither dominates or oppresses the other. Oppression means treating a fellow being as an object, a thing apart. When this happens, both the oppressor and the oppressed are unfree and must be liberated to greater humanity. If we regard mentally retarded people as objects to be cared for, we become objects ourselves. We become tools and aids in the world. We acquire the same limited function as invalid chairs and artificial limbs, and we must be helped by the mentally retarded to reconquer our humanity.

Their experiences must be ours

The mental nurse occupies by tradition a position of power in relation to the mentally retarded persons he (or she) works with. He produces care, suggestions and ideas which are consumed by the mentally retarded. This is the traditional model. But if we want our work to amount to something different from arranging meetings between producers and consumers, experts and patients, we have to approach the mentally retarded individual as a fellow human being. One of the necessary prerequisites of our work together with the mentally retarded is our own capacity for understanding through identification. We can never understand our fellow beings in the light of theories and models. We must share their feelings.

Understanding of these kind can only be achieved when the central experiences, hopes and disappointments of the members of the group coincide with

our own. Experiences of dependence, compulsion and emancipation are common to all human beings. As children we have all experienced feelings of being left outside, inferior and at a disadvantage, and in most of us these feelings are still not very far below the surface. The fear of being weak, not coping, not succeeding, or looking stupid is deeply rooted within us. As therapists, nurses or fellow beings, we can understand the mentally retarded from inside ourselves, because we have access to our own uncertainty, fear, smallness and loneliness.

Without this fundamental recognition, we cannot understand a mentally retarded person's experience as an experience which could happen to us.

But there can be risks involved in listening openly and actively. By entering into the thoughts and opinions of another person, we see the world for a moment as he sees it. It feels as though we are the ones who are being forced to change - forced to think again and see ourselves as others see us. We risk abandoning the security of our accustomed values in order to try to think together with another person and along the same lines as he does.

No group of people can be so easily oppressed as the mentally handicapped. Looking at the role of the custodian, either in the administrative sector or in the direct business of looking after people, we may ask why we feel so much at home in it. Why do we work with the mentally retarded? What makes us work with the most powerless, incompetent and silent? Could the reason be that in this way we have such a wonderful opportunity of experiencing our own power and strength?

#### Interview with Siv

The discussion group approach is best illustrated by showing how it works in practice, and so I am going to tell you about Siv, who is moderately retarded and has been with the group for two years.

Siv lives in the Cottage ward of the big nursing home. She shares a room with two other patients, and she does not like this because they will not leave her things alone and they disturb her at night. At the first group

session

several of the members said that they wanted to move. Siv cautiously agreed.

This subject was raised again at the second group session. We spoke about who decided on moves and about this question often being decided by other people. Siv did not say anything.

Group leader: What do you think, Siv?

Siv: I like being here, I do. Being here and helping to make the beds and look after the ones who can't walk - and washing up.

GL: You've changed your mind a bit since last time, haven't you?

Siv: Yes.

GL: Why?

Siv: The staff like having me here to help. They think I'm clever.

It was important to Siv that she should be liked - so important that she was prepared to sacrifice quite a lot of the other things she attached importance to.

The other members of the group continued criticizing the Cottage. It was noisy there and they wanted to be somewhere where things were more peaceful. Siv did not say anything.

GL: Don't you think it's noisy there, then, Siv?

Siv: I like helping. I don't mind them arguing. I don't listen in the evenings.

Arne: Her Dad won't let her move.

Siv: I like helping to make the beds.

GL: What things do you help with in the ward?

Siv: I lift the ones who can't stand up - hold them up in bed. I take away the dirty clothes and all that. I <sup>clean</sup> the toilets too. Lay the table and do all sorts of things. I've talked to my Dad about how I'm to be here and help make the beds - and help the one who can't manage by themselves - my Dad said.

GL: Your Dad said that. Arne says your Dad won't let you move.

Siv: No. Yes, I talked to my Dad when I went home - I did. He thought I should stay here.

GL: He said you were to stay here at the Cottage, though you've said yourself that you want to move. What do you really think?

Siv: I like it here.

The last answer showed that Siv was willing to efface herself in order to retain the affection of the staff and her

father. At the next group session we talked about having a room of your own. Siv did not say anything.

GL: Siv, would you like to have a room of your own?

Siv: No, they say I can't look after it.

GL: Who are "they"?

Siv: The staff.

GL: What is it you can't do? What it is you can't learn to do?

Siv: Well, I can make beds, can't I? I make all the beds.

GL: What else needs doing in a room? Hoovering?

Siv: Yes, I can do that - because I did it when I was home.

GL: Have you ever hoovered at the Cottage?

Siv: No, I mustn't use the hoover in the ward.

GL: But then all you need is practice.

Siv: Yes, I should think I could learn that.

GL: Yes.

Siv: You <sup>have</sup> to dust as well, and I can do that.

Kjell: You ought to move; you're clever.

Siv: I've got to stay and help make the beds and wash the girls.

We continued talking about differences between the members of the group and the staff - for instance, about the staff being there to help the patients become independent. Siv now <sup>became</sup> involved in a major conflict with herself. She still felt that she <sup>was getting</sup> too little affection from the group to dare to declare her feelings openly. She <sup>stayed</sup> away from the group a few times until the other members asked her to come back.

Let us consider Siv's awareness at this juncture. She very much desired a room of her own, but she was under the delusion that she would not be able to look after it. The only way in which she can satisfy her need for affection was by staying on and helping out. She denied this need completely by saying that it was fun being there and helping out. She seemed to experience great anxiety at the prospect of having to make and be responsible for a decision of her own: "I've talked to my Dad about I've got to stay here, my Dad says". Siv is not aware that she possesses <sup>powers</sup> ~~do not~~ of her own with which to transform her situation. "World, be transformed!" <sup>seem</sup> to be her attitude. She adjusts to the superior power of the staff and her father by submitting and denying her needs. Rebellion involves too many risks for her.

We are now going to take quite a leap in time, resuming our story about a year later. Siv had not had much to say in the group. She had sat there very quietly. During the past few sessions she had directed aggressive outbursts at the others when they talked too much, but she had not been able to make use of the attention she obtained.

This was her breakthrough.

Pär: Aren't I allowed to walk by myself?

GL: Yes, people must be allowed to do that. What do you say, Malin?

Malin: Yes, when you can look after yourself.

Siv: I don't want to go to therapy tomorrow. I won't. They keep on at me about I must go to therapy. I won't, no I won't. I have to take the others to therapy. I won't, so there.

GL: Don't you like it?

Siv: No, I'm fed up with going to therapy. I won't go with that bloke Lena and those other girls to therapy. I won't, so there.

GL: Then would you like to go by yourself?

Siv: I don't want to have Anna at therapy. Nor Lena and that other one who can't talk.

GL: So you'd like to go by yourself?

Siv: Yes!

GL: Really?

Siv: You have to hold her hand and walk ... just like a mother does. Ugh, no. Ugh!

GL: You're getting tired of being mother?

Siv: Yes, I'm fed up with them.

GL: You don't want to look after them any more?

Siv: The staff keep on at me and saying I have to: 'Hurry up and make the beds. Hurry up and make the beds'. They keep on and on at me. I'm getting fed up with it. I told them, 'I'll get it done'.

GL: Really?

Siv: I told them, 'Stop going on at me'.

GL: But let's get this straight, are you the one who has to make the beds at the Cottage?

Siv: Yes, I'm the only one who makes the beds. The others don't do anything.

GL: Then, why do you make the beds?

Siv: They never teach Anna and the others to make the beds - they never do. But I told Anna, 'You'll have to learn to dress



yourself. And she had to put her slacks on by herself, because she can'.

Clearly, then, Siv's dependent identity was a false identity. Her inability to take responsibility for her life had resulted from her situation of total dependence. Her earlier view of herself was a reflection shown to her by the staff and her father.

Siv had begun to discover how she was being exploited and oppressed. The staff thought she had got "worse". She was no longer prepared to co-operate on their terms. Would she be able to make them "discover" her? After another couple of weeks, Siv's situation had changed completely.

Siv: The staff say I can move if I like.

GL: Have you asked them now?

Siv: I said I didn't want to be here any more.

GL: Oh?

Siv: 'Can't you stay?' they said. 'No,' I said.

GL: Oh?

Siv: 'Can't you stay here and help us with the girls?' they said. 'No, I've made up my mind now,' I said, 'I want to move.'

Siv had broadened her awareness of herself as a person with the power to demand changes in her situation. She had made the staff discover this.

The oppressor must be liberated, because the role of oppressor prevents him from expressing his humanity, the characteristic of which is mutuality. But the oppressors cannot be pointed out as a special sort of person; most people are both oppressors and oppressed.

Siv illustrates this dual role of oppressor. She herself turns the other mentally retarded inmates of the ward into "objects" through her staff role. She oppresses the other patients and is in turn oppressed by the staff. It is a case of the biter bit - the oppressor oppressed. It is only when she gets cross with those she "oppressively assists" that, for the first time, she reacts to them emotionally as individuals. By emancipating herself she emancipates both the oppressor and the oppressed within herself. Only then is she capable of providing for her own genuine needs. Only then does she have the opportunity and the capacity to begin shaping her life.

Siv eventually moved from Solgården to Skogly. A friend who called on her reported that she was very pleased with her new home, where there were six men and women living together in a detached house. When Siv was asked whether they did their own cooking in the house, she answered in the negative. The staff corrected her and said, "But we do". "No," Siv insisted. "But we do," the staff said. "Yes, you do - but I don't," Siv said, and this went to show that Siv had now achieved a clear realization of the differences between herself and the staff. This realization was important.

### Training and adjustment

Our view of the individual receiving institutional care depends on the view we have of people and society. It depends on whether we believe that man has an innate capacity for social responsibility and active creativity or that he can only be developed by means of external control; our beliefs in this respect have a practical impact on the care we provide.

For some years now, views concerning the mentally retarded have been determined by the training orientation of psychology. The principal theme of the official ideology of care is training and adjustment - external control, in other words. Training pedagogics came as a doctrine of salvation. People now knew what to do as parents, teachers, staff or psychologist. Everybody could be trained. The thing was to create motivation. A mentally retarded person was not expected to have any motivation other than that created for him.

Nobody asked what the mentally retarded individual wanted to be trained for. There was no discussion of the role which the mentally retarded individual himself should play in his own training, adjustment and development. What is that role? In the ultimate analysis, does not the training ideology imply an assumption that the mentally retarded are incapable of initiative and action and that it is only by external factors that they can be led, manipulated towards a desirable pattern of behaviour?

In one of my discussion groups we found after a year that the institutional environment was too constricted a framework for our sessions; the group was ready to venture

further afield. We arranged premises in the community outside the institution. None of the people in the group had travelled alone before; they were used to being driven collectively whenever they went anywhere. They had never been told or invited to try and fend for themselves outside the institution, and the staff anxiously queried our joint decision. I travelled with them just once, and since then they have travelled by themselves. Sometimes they went the wrong way, but this did not really matter. Anybody who travelled the wrong way saw his mistake sooner or later and caught the next bus back again. The members of the group have subsequently extended the area in which they are able to travel by public transport, and they have not had much difficulty in realizing their limitations in this respect.

On what grounds had these people been denied for so many years the right to travel as free individuals? The answer is: in their own best interests, to protect them. But this is a dangerous way of protecting a fellow human being, because it prevents him from acquiring vital experience. You cannot learn anything if you are not made responsible for your own learning.

### The institutional structure

The main factor from the viewpoint of a mentally retarded person in an institution is not that he has difficulty in adjusting to life in the community at large; instead it is the institutional structure itself that limits his opportunities of gathering experience "at liberty".

Learning how to put things across to administrators, teachers, staff, therapists and other mentally retarded persons is more important than knowing how to withdraw money from your savings account. Before you can become your own master, you have to become aware of your humanity, your bodily functions and the legality of your needs. A mentally retarded person who has doubts in these respects cannot make decisions of his own.

A mentally retarded person in the dehumanized surroundings of an institution can respond to his environment in various ways - by submitting, by acquiescing, by being passive, by becoming an object ruled by others, by showing indifference, by retreating into his shell, by indulging in outbursts of rage, by getting depressed, by

nagging, by talking nonsense, by protesting, revolting and demanding his rights. In other words, the mentally retarded can respond by individual behaviour to the challenges with life confronts them, just as we ourselves can. They create themselves by the way in which they react. Saying, or just thinking, that you want to move, for example, is a form of transcendence. You begin to see yourself as an individual capable of breaking bounds.

This does not mean that I consider all training to be worthless; it simply means that the mentally retarded individual himself must "rule" the training he receives. Training must be governed by his own need for meaning and satisfaction. We have to ask ourselves what the mentally retarded individual wants to learn and what he himself thinks that he needs.

Our view of motivation is crucial to the view we take of people's ability to develop on the basis of their own needs. The mentally retarded have the same motivation as other people for development and learning. Of course, they do not have the same potential, but they must be allowed to play a part in shaping their own living situation according to their own needs and aptitudes.

The methods employed in ADL and social training have been designed in large institutions and are based on creative training situations. If we build institutions with large central kitchens, there is no point in the inmates learning to cook. There is no point learning to cook in a training flat if your knowledge will not come in useful in the ward. There is no point in learning to handle money if all the money is in the office. There is no point in learning about travelling and road sense if your knowledge is not needed in the practical context. There is no point in knowing anything if nobody notices your knowledge. There is no point in talking if nobody listens.

Even the gravest cases

My work with discussion groups has convinced me that, if only they are given the chance, the mentally retarded can influence their surroundings. Many mentally retarded persons with slight and moderate intellectual disabilities are intellectually capable of reflecting on themselves and their actions. They are also capable, therefore, of influencing and changing

their situation. This is readily forgotten, however, because we ourselves are often manipulated and oppressed.

One category of mentally retarded, persons with severe intellectual disabilities and supplementary physical handicaps, are often described like objects or "packages". When they are characterized as manageable packages, this means that they are not credited with the fundamental human needs of contact and mutuality. Few people, however, are so gravely retarded as to lack all communicative ability. Physical (motoric) and mental obstacles do not preclude all communication. A severely retarded person, like a newborn baby, is capable of giving non-verbal signals and messages.

As I say, practically every mentally retarded person is capable, one way or another, of expressing himself and "making demands". But our well-developed brains cannot help us to receive and translate such messages. We have to use our hands, our bodies, in our dialogue with the gravely retarded. Frederick Leboyer speaks of the universal language - sense - which comes long before verbal language. He speaks of "the infinite insight and sensitivity of the skin". Thus one cannot establish genuine contact with a severely retarded person without finding his sphere of experience. Skin talks to skin. Movement communicates with movement. Thus Leboyer:

"He knows whether the hands like him.

Or whether they are absentminded.

Or worse still, whether they will not have anything to do with him."

Thus a severely retarded person is not an object but an active being who discovers, observes and experiences. It is only through active listening, through trying to enter into a dialogue with him, that we can identify his needs.

#### Our new role

One thing which those of us who work with the mentally retarded have to decide is whether we are going to work for the liberation of their human possibilities of active participation and influence or whether we wish to work to adapt them to a given environment and living situation. Do we want the mentally retarded to be able to act as subjects and build up their personalities by doing so? Do we want them to become aware of

their ability to influence and transform their surroundings? If so their relation to us must be that of subjects, not objects. They must become "you", instead of "it", "him", "her" or "they". This demands a profound emotional understanding on our part which affords no scope for manipulation and is instead aimed at adjusting the mentally retarded individual to himself. Instead of deciding things for the mentally retarded, we must help them to acquire self-confidence and the ability to say what they want - the ability to decide, to control their own situation, even if this does not always concur with our interests. They must be able to see that activity is meaningful and worth while.

We cannot accept the idea that the values applying to the mentally retarded are different from those applying to ourselves. In our work with the mentally retarded, therefore, there are a number of things which we have to deny. We must deny the relegated status of the mentally retarded. We must deny the "immutable" rules and regulations of the institution. We must deny authority. We must deny other people's right to control the mentally retarded and ourselves. The role of the mentally retarded and the foundation of their existence must be sought through challenge and denial and not through adjustment.

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# Literature

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